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Access, use and satisfaction with physiotherapy services among adults with cerebral palsy living in the United Kingdom and Ireland

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ABSTRACT

Purpose: The aims of this study were to describe how and why adults with CP living in the UK and Ireland accessed and used physiotherapy services; to describe the type of physiotherapy accessed and satisfaction with physiotherapy services and to examine the associations between relevant factors.

Methods: A cross-sectional semi-structured online survey was employed. Participants were adults with CP aged 18 and above living in the UK and Ireland; able to complete an online questionnaire in English independently or with technical or physical assistance. Data were collected from April 2019 to February 2020.

Results: Participants ($n = 162$) were aged 18–74 years. The majority were female (75%) and lived in the UK (83%). Ninety percent of participants reported a need for physiotherapy but only 35% received physiotherapy services. The most common reason for visiting physiotherapy was mobility decline (62%). Satisfaction with the availability and quality of physiotherapy services were 21% and 27%, respectively. Adults with scoliosis and mobility decline were less likely to report that they received the physiotherapy they needed.

Conclusion: Adults with CP did not receive the physiotherapy services that they perceived they needed. There is a need to develop physiotherapy services in collaboration with people living with CP.

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Adults; cerebral palsy; physiotherapy services; accessibility; satisfaction

► IMPLICATIONS OF REHABILITATION



- Adults with cerebral palsy (CP) needed physiotherapy services, but were not receiving the physiotherapy services that they perceive they needed.
- Adults were not satisfied with the availability or quality of physiotherapy services received.
- Adults with scoliosis and mobility decline were less likely to report that they received the physiotherapy they needed.
- There is a need to develop physiotherapy services from a life-span perspective for adults living with CP.


Introduction

Cerebral palsy (CP) is a lifelong neurodevelopmental condition [1]. People with CP present with primarily motor as well as cognitive, hearing and speech impairments, and/or epilepsy [1,2]. The motor impairments associated with CP continue to affect activity and participation as the individual matures into adulthood [3]. Adults with CP are less physically active [4] and have a higher risk of non-communicable diseases compared to their peers without CP [5,6]. Further, many adults with CP experience musculoskeletal pain, fatigue, deterioration in walking ability, reduced muscle flexibility, strength and endurance, reduced balance and increased falls [7–12]. A recent study in the US using a larger cohort of adults with CP and musculoskeletal diagnosis reported that when

compared to those without CP, older adults had a higher prevalence of soft tissue disorders (87%), joint pain (61%) and bone or cartilage disorders (50%), but a significantly lower proportion of them used physiotherapy services [13].

Physiotherapy is an integral part of rehabilitation for many children with CP to address motor and functional impairments [14]. As adults, many people with CP require physiotherapy services to meet their ongoing physical and functional needs. A systematic review conducted recently reported that physiotherapy is the most commonly used rehabilitation service (44%) among adults with CP [15]. In qualitative studies, adults report using physiotherapy to help with pain, stiffness and fatigue [16,17]. Adults also report that physiotherapy has a positive effect on reducing pain, and improving or

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maintaining functional skills and muscle strength [18]. Despite the potential benefits of physiotherapy, many adults with CP who report that they need physiotherapy are not receiving it [19,20]. Even when adults receive physiotherapy, findings from qualitative studies suggest that the physiotherapy provided to adults with CP is not always appropriate to meet their needs [21–23].

Adults with CP may not receive physiotherapy that meets their needs because of financial barriers or lack of transport [22]. Further, factors relating to the person and their CP, such as age, sex, area (urban, or rural), the severity of motor impairment, presence of secondary complications of CP (scoliosis), surgical intervention, and age-related complications in CP (pain, mobility decline, falls, fatigue) may influence whether or not they receive the physiotherapy they need. Adults also report challenges in finding a physiotherapist with an interest in CP [24], and physiotherapists with knowledge and expertise about CP [21,22], which possibly affects their satisfaction with physiotherapy services. In a study of people with CP, adults were less likely to be satisfied with motor rehabilitation, which included physiotherapy services, compared to children [25]. However, it remains unclear from the study if the dissatisfaction is related to a lack of availability of physiotherapy or the perceived quality of physiotherapy services.

Internationally, there is evidence that adults with CP need physiotherapy, and even when received, physiotherapy may not be appropriate to meet their needs. However, there is a lack of evidence on the type of physiotherapy used by adults with CP, the referral pathway to physiotherapy services, and satisfaction with the availability or quality of physiotherapy. Further, existing studies that describe the challenges related to accessing physiotherapy services are qualitative. In the United Kingdom (UK), physiotherapy services are provided by the public National Health Services (NHS) [26], and charitable organizations. The NHS service is free of charge, but the funding mechanism for charities varies. Some charities part-fund their fees through charitable donations and charge the remaining part either directly to the service user or other funding streams. Similar to the funding, the referral pathways are not consistent in the UK. NHS services are predominantly through GP referral, but in some instances, service users can self-refer. However, charitable organizations have mixed funding and referral mechanisms. In Ireland, state-funded physiotherapy services are provided by the Health Service Executive (HSE) or voluntary or charitable organizations, which may also receive funding from the HSE [27]. The services that receive funding from the state are free of charge. Referral streams are not consistent in Ireland. Adults are referred to physiotherapy services by their GP, consultants or allied health professionals (physiotherapist, occupational therapist and nurse) within their catchment area. Adults may also access private physiotherapy services that are self-funded and self-referred both in the UK and Ireland. In the United Kingdom (UK) and Ireland, there is an increasing focus on developing health services that meet the needs of adults with CP [28–30]. Quantitative data describing the current need for and experience of physiotherapy among adults with CP may inform and justify the development of appropriate physiotherapy services.

Therefore, this study aimed to describe how and why adults with CP living in the UK and Ireland accessed and used physiotherapy services; to describe the types of physiotherapy accessed, and satisfaction with physiotherapy among adults with CP. A secondary aim was to examine the clinical and demographic factors that are associated with needing physiotherapy and receiving physiotherapy that meets their needs. The objectives are as follows:

1. To describe the percentage of adults with CP who need physiotherapy and the percentage who receive the

physiotherapy they need, and the reasons adults with CP seek physiotherapy.

2. To describe the types of physiotherapy used by adults with CP, referral pathways to physiotherapy, and accessibility of physiotherapy services.
3. To describe satisfaction with the availability and quality of physiotherapy among adults with CP.
4. To examine demographic and CP-related characteristics that are associated with the need and receipt of physiotherapy among adults with CP.

Methods

Study design

A cross-sectional survey design was used to address the aim of this study. The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [31] and Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines were used [32].

Participants

Adults with CP aged 18 and above; living in the UK or Ireland; ability to complete an online survey in English with or without technical or physical assistance; accessed or tried to access physiotherapy services at least once in their adult life (i.e., from age 18 years) were included.

Survey

The survey was developed using established design principles for surveys [31,33] and by reviewing previous studies that used surveys to evaluate physiotherapy [34–38]. It was developed in collaboration with an advisory panel of physiotherapists and people with CP. The survey was piloted by nine members of the advisory panel and research team and adapted based on the feedback obtained. Specific aspects assessed during piloting included time to complete, clarity and relevance of questions, and ease of navigating through the questions. Information about the study was included on the first page of the survey. The information included the purpose of the study, eligibility criteria, duration of the survey and potential risks and benefits of taking part. The survey was not specifically enabled for augmented or alternative communication.

The survey was hosted on onlinesurveys.ac.uk and took approximately 20 min to complete. Participants were informed that the survey was entirely voluntary and completed anonymously. Potential participants were invited to contact the research team if they had questions or for further information about the study. Participants were requested to select a statement that they consented to participate in the survey before proceeding to complete the survey. Completion of the survey indicated consent. Data obtained from the survey was fully anonymised and downloaded from online surveys as an excel sheet. The survey was divided into sections as follows: (1) Demographics such as age, sex, country, and employment status; (2) CP-related characteristics such as type of motor impairment, and Gross Motor Function Classification System (GMFCS) level (Respondents were provided with a description of each GMFCS level in plain English and asked to select the descriptor that best described their level of functional mobility), presence of epilepsy (a common impairment that can change over time and requires careful monitoring over the life course) [39]; (3) Commonly reported complications of CP as reported in the literature [28] and by the advisory group were assessed. The survey

included pain (assessed using a visual analogue scale of severity of pain experienced in the previous seven days), falls (defined as a fall slip or trip that resulted in landing on a lower level in the past year, number of falls reported), visual impairment (a component of a falls risk assessment), mobility decline since turning 18 years (reported as yes or no), and fatigue measured on the Fatigue Severity Scale (FSS) [40]; (4) Need for physiotherapy and whether or not the person received the physiotherapy they needed (hereafter referred to as “received adequate physiotherapy”), and reasons for seeing a physiotherapist; (5) Type of physiotherapist seen (e.g., neurological or musculoskeletal physiotherapist), type of physiotherapy service used (e.g., public health provider, private provider, charity), ease of referral to a physiotherapist, and access to physiotherapy services which includes convenience in time accessed, funding source, transport challenges; and (6) Satisfaction with the availability and quality of physiotherapy services. Closed-ended questions were used predominantly, but some open-ended questions were included to allow the participant to provide more detail when they selected an “other” option. For all closed-ended questions, the selection of one response was mandatory. However, participants had the option to select “prefer not to say.”

Data collection

The survey was available online between April 2019 and February 2020. The strategy for sharing the survey was discussed and developed with the advisory panel. The survey link or paper version was shared with 45 organisations, disability bloggers and support groups that provide services and supports to people with CP or disabilities in the UK and Ireland. Of these, 35 responded to confirm they would share it *via* a newsletter, mailing list, website or social media platform, and ten organisations and support groups did not respond or refused to share it. The survey was also advertised at a conference for physiotherapists, and people with CP; professionals and researchers in the UK hosted by a charity for adults with CP. Adults with CP and health professionals that worked with adults were asked to share the survey with people in their networks.

Data analysis

Data were analysed using Stata version 16. Descriptive statistics were used to summarise data relating to demographics, CP-related characteristics, complications of CP, need for physiotherapy, received adequate physiotherapy, reasons for accessing physiotherapy, type of physiotherapy used, referral pathway, convenience in time accessed, funding source, transport challenges to access, and satisfaction of physiotherapy services. Continuous data were described using means, standard deviations, medians, interquartile range, or range as appropriate. Categorical data were described using numbers and percentages. Comparisons were made between the UK and Ireland using Chi-squared tests or Fisher’s exact tests, as this may be of interest for policymakers and decision makers in developing physiotherapy services in the UK and Ireland. Logistic regression was used to explore associations between the independent variables and outcomes. The outcome of interest were those who (1) needed physiotherapy and (2) received the physiotherapy they needed. The independent variables were age, sex, GMFCS level, area of living, pain, fatigue, scoliosis, mobility decline, surgery under 18, surgery as an adult and falls. These independent variables were identified by our Public and Patient (PPI) contributors who are adults with CP and service providers working with adults with CP. Firstly, unadjusted analyses were conducted, with one independent variable and one outcome. If the independent

variable was associated with the dependent variable at $p < 0.10$ in the unadjusted model, then we included it in a final model. The final model included all independent variables that were associated with the dependent variable at $p < 0.10$. We assessed the Hosmer-Lemeshow test to evaluate the goodness of fit, and there was no evidence of poor model fit.

Results

Overall, 162 people with CP completed the survey (Table 1). Eighty-three percent were from the UK. A third of the participants

Table 1. Participant characteristics ($n = 162$).

	<i>n</i>	%
Age		
18–24 years	25	15.4
25–34 years	56	34.6
35–44 years	41	25.3
45–54 years	21	13.0
55–74 years	19	11.7
Sex ^a		
Male	40	24.7
Female	121	74.7
Country ^b		
England	101	62.4
Ireland	24	14.8
Wales	16	9.9
Scotland	11	6.8
Northern Ireland	7	4.3
Ethnicity ^c		
White British	117	72.2
White Irish	29	17.9
Mixed multiple ethnic groups	5	3.1
Asian or Asian British	4	2.5
Black/African/Caribbean/Black British	3	1.9
Other	2	1.2
Area ^a		
Urban area (city, town)	111	68.5
Rural area (countryside, village)	50	30.9
Work status ^d		
Full-time work	41	25.3
Part-time or casual work	35	21.6
Not working (looking/ not looking for work)	35	21.6
Voluntary work	17	10.5
Full or Part-time post 18 education (college)	15	9.3
Retired and other	13	8.0
Type of motor impairment ^c		
Bilateral spastic CP	74	45.7
Unilateral spastic CP	47	29.0
I don’t know my diagnosis	17	10.5
Ataxic	11	6.8
Dyskinetic	8	5.0
Other	6	3.7
Mixed CP	2	1.2
GMFCS ^a		
I	15	9.3
II	63	38.9
III	40	24.7
IV	28	17.3
V	15	9.3
Secondary problems		
Epilepsy ^b	14	8.6
Scoliosis ^b	73	45.1
Eyesight problems ^c	95	58.6
General practitioner (GP) ^b seen in the past year	153	94.4
Number of visits to GP in the past year ^b		
1–3 times	67	41.4
4–6 times	57	35.2
7–11 times	17	10.5
12–15 times	6	3.7
More than 15	6	3.7

^a $n = 161$, remainder selected prefer not to say. ^b $n = 159$, remainder selected prefer not to say. ^c $n = 160$, remainder selected prefer not to say. ^d $n = 156$, remainder selected prefer not to say.

were 25–34 years old and a quarter of participants were 35–44 years. Seventy-five percent of participants were female, 69% lived in an urban area, 57% were in paid or voluntary employment and 22% were unemployed. The majority of participants were White British (72%).

Nearly half of the participants had bilateral spastic CP (46%), 29% had unilateral CP, 12% did not know the type of motor impairment they experienced, and the remainder had other types. Approximately 39% of adults were in GMFCS level II and 25% were in level III. Approximately 9% of adults had epilepsy, of whom 79% said their epilepsy was under control and 17% said they regularly saw a doctor about their epilepsy. Forty-five percent reported having scoliosis, of whom 26% saw a health professional for their scoliosis. Nearly 60% reported eyesight problems; 82% of these adults had a regular review of their eyesight. Sixty-one percent of adults reported having surgery related to CP as a child and 29% had surgery for CP as an adult. Overall, 94% of participants saw their General Practitioner (GP) in the past year, with 59% visiting their GP 4 or more times per year.

Table 2 describes complications of CP experienced by participants. Seventy-eight percent experienced pain for more than 3 months. Of these, 87% reported that pain interfered with activities of daily living (ADL). Approximately, 78% of adults reported at least 1 fall in the past year, with 24% experiencing more than 10 falls in the past year. Thirty-one percent reported that they experienced a fracture or severe sprain as a result of a fall. Eighty-three percent of adults reported a decline in mobility since turning 18 years of age, and 63% of the participants reported experiencing a decline in mobility in the past year. The median (IQR) score on the FSS was 48 (35–58) on a scale of 9–63.

Need for physiotherapy, receipt of physiotherapy, and reasons for seeking physiotherapy

Ninety percent of participants reported that they needed physiotherapy in the past year, of whom 35% received all the physiotherapy that they felt they needed. When analysed for differences between the UK and Ireland, there were no significant differences in the response for need and receipt of physiotherapy (Supplementary Appendix). The most frequently reported reasons for seeing a physiotherapist as an adult were mobility decline (62%), stiffness (57%), pain (54%), spasticity management (51%) and joint pain (44%) (Table 3).

Table 2. Complications of CP ($n = 162$).

	<i>n</i>	%
Pain for more than 3 months	126	77.8
If yes, pain interferes with ADL ^a	109	86.5
If yes, pain intensity in last 7 days assessed on VAS, median (IQR) ^a	5 (4–7)	
Falls in the past year ^b	126	77.8
Number of falls in the past year ^b		
1–5 times	66	40.7
6–10 times	21	13
11–14 times	6	3.7
>15 times	33	20.4
Experienced a fracture or severe sprains from falls or accidents ^c	50	30.9
Don't Know if they experienced complication from fall	7	4.3
Mobility decline since 18 year ^b	134	82.7
Mobility decline in the last year ^b	102	63
Fatigue severity scale ^d , median (IQR)	48 (35–58)	

^aCalculated for the sample in pain $n = 126$. ^b $n = 159$, remainder selected prefer not to say; ^c $n = 161$, remainder selected prefer not say. ^dPossible range 9–63; higher score indicates greater severity. IQR: Interquartile range; SD: Standard deviation; VAS: Visual Analogue Scale.

Type, referral and access to physiotherapy services

Table 4 describes the type of physiotherapy used by adults, referral pathways and accessibility of physiotherapy. Eighty-one percent of adults' physiotherapy was through public service providers. Approximately 67% of the adults reported their physiotherapy treatment was funded by public service providers. Of the 78% of participants who knew their physiotherapists' speciality, 40% reported seeing a non-specialist physiotherapist, 33% reported seeing a physiotherapist who specialised in neurology and 29% reported seeing a physiotherapist who specialised in musculoskeletal physiotherapy. Participants could report seeing more than one type of physiotherapist. Forty percent of adults reported that their GP usually refers them to physiotherapy, and almost a third stated that they organise the referral themselves. Twelve percent of adults reported it was easy to find a specialist physiotherapy service. Nineteen percent reported it was easy to get referred to a specialist physiotherapy service either through their doctor or other healthcare practitioners. Thirty-two percent of participants agreed or strongly agreed they could access physiotherapy services at a convenient time. However, more than a third of the participants (37%) reported transport and parking were inadequate to meet their needs. There were no significant differences in the response for accessibility to physiotherapy between the UK and Ireland (Supplementary Appendix).

Satisfaction with the physiotherapy services

Forty-three percent of adults reported that the physiotherapists they consulted were not usually experienced in working with

Table 3. Reasons for using physiotherapy as an adult ($n = 162$)^a.

	<i>n</i>	%
Mobility decline	101	62.4
Stiffness	92	56.8
Pain management	87	53.7
Spasticity management	82	50.6
Joint pain	72	44.4
Improve ability to exercise	59	36.4
Manage fatigue	43	26.5
General advice	43	26.5
Following a fall/accident (new/acute injury)	35	21.6
Following surgery	31	19.1
Improve sleep	27	16.7
Help breathing	8	5
Other	4	2.5
Prefer not to say	2	1.2

^aParticipants could select more than one option.

Table 4. Type, referral and access to physiotherapy services ($n = 162$).

	<i>n</i>	%
As an adult, which types of physiotherapy services have you used? (tick all that apply)		
NHS/Public	131	80.9
Private practice	60	37.0
Charity	21	13.0
Other	7	4.3
Prefer not to say	4	2.5
As an adult do you usually see a physiotherapist who is: (tick all that apply)		
A general physiotherapist (non-specialist)	65	40.0
A specialist in neuro physiotherapy (a neuro physio) ^a	54	33.3
A specialist in musculoskeletal physiotherapy (orthopaedics) ^a	47	29.0
Don't know	35	21.6
Who usually makes your referral to physiotherapy?		
General Practitioner (GP)	65	40.1
I organise it myself	51	31.5
National Health Service (NHS)/Public Hospital consultant (e.g., a specialist doctor; neurologist, orthopaedic surgeon)	25	15.4
Other	12	7.4
Private consultant	3	1.9
I wait until my physiotherapist contacts me	3	1.9
Prefer not to say	3	1.9
I could see a physiotherapist at a time that was convenient to me ^b		
Strongly disagree	31	20.9
Disagree	30	20.2
Neither agree or disagree	38	25.6
Agree	32	21.6
Strongly agree	16	10.8
Prefer not to say	1	0.7
Transport and parking were adequate to my needs ^c		
Strongly disagree	19	14.2
Disagree	31	23.1
Neither agree or disagree	26	19.4
Agree	36	26.9
Strongly agree	20	14.9
Prefer not to say	2	1.5

^aSpecialist physiotherapists are those who completed post-graduate training in their field and/or worked exclusively with people with neurological or musculoskeletal conditions in the UK and Ireland. ^bPercentage calculated for those reported applicable ($n = 148$). ^cPercentage calculated for those reported applicable ($n = 134$).

adults with CP. Only Twenty-one percent of adults were satisfied with the availability of physiotherapy services, and 27% were satisfied with the quality of physiotherapy received. There was no significant difference between the UK and Ireland (Supplementary Appendix).

Factors associated with need and receipt of adequate physiotherapy services

Unadjusted associations between independent variables and needing and receiving adequate physiotherapy are described in Table 5. In unadjusted analysis, there was evidence that pain (OR: 2.58, 95% CI: 0.85–7.81; $p = 0.094$), mobility decline (OR: 2.97, 95% CI: 0.99–8.83; 0.050) were positively associated with needing physiotherapy. Scoliosis (OR: 0.50, 95% CI: 0.25–1.02; $p = 0.058$) and mobility decline (OR: 0.48, 95% CI: 0.23–0.99; 0.048) were negatively associated with receiving adequate physiotherapy.

In the final model, there was no association between pain and needing physiotherapy after adjusting for mobility decline (OR: 1.65, 95% CI: 0.46–5.93; $p = 0.441$). Similarly, there was no association between mobility decline in the past year and needing physiotherapy after adjusting for pain (OR: 2.36, 95% CI: 0.68–8.26; $p = 0.176$).

After adjusting for mobility decline in the past year, adults with scoliosis were 0.45 times (95% CI: 0.21–0.93) less likely to receive the physiotherapy services they needed ($p = 0.031$). After adjusting for scoliosis, people with mobility decline in the past year were 0.43 times (95% CI: 0.20–0.90) less likely to receive the physiotherapy services they needed ($p = 0.026$).

Discussion

This study aimed to describe how and why adults with CP accessed and used physiotherapy services, types of physiotherapy accessed, satisfaction with physiotherapy services and factors associated with physiotherapy needed and physiotherapy received among those who perceived they needed it. Most of the adults included (90%) reported needing physiotherapy in the past year, and of these only, 35% reported receiving the physiotherapy they needed. The most common reason for seeking physiotherapy was mobility decline (62%). The majority of adults with CP accessed physiotherapy through public service providers (81%) and were referred by their GP (40%). A low proportion of adults were satisfied with the availability (21%) and quality of physiotherapy services (27%) received. Adults with scoliosis and mobility decline were less likely to receive the physiotherapy they needed. The findings highlight that people with CP need physiotherapy throughout their lifespan, and currently, physiotherapy services available to adults with CP in the UK and Ireland do not meet their needs.

Few studies have reported the proportion of adults with CP that need physiotherapy. Data from Ireland and Korea indicated that between 23 and 36% of adults needed physiotherapy, which was lower than the current study findings [19,41]. This may be because the survey introduced volunteer bias. Of the 90% of adults who reported that they needed physiotherapy services, only 35% received the physiotherapy services that they felt they needed. We are unable to compare our findings to previous research as there is a lack of studies that examine if adults with CP receive the physiotherapy they perceive they need. Previous qualitative research indicates that access to physiotherapy services

Table 5. Unadjusted associations with needing and receiving adequate physiotherapy.

	Needed physiotherapy OR (95%CI); <i>p</i> -value	Received adequate physiotherapy OR (95%CI); <i>p</i> -value
Age	(<i>n</i> = 142)	(<i>n</i> = 143)
18–24 years	(reference)	(reference)
25–34 years	0.89 (0.16–4.91); 0.891	0.97 (0.34–2.72); 0.948
35–44 years	0.41 (0.08–2.15); 0.292	1.12 (0.37–3.44); 0.836
45–54 years	1.74 (0.15–20.65); 0.661	1.09 (0.30–3.88); 0.890
55–74 years	1	1.09 (0.31–3.88); 0.890
Sex	(<i>n</i> = 160)	(<i>n</i> = 143)
Male	(reference)	(reference)
Female	0.57 (0.18–1.81); 0.337	0.73 (0.32–1.69); 0.464
Pain more than 3 months	(<i>n</i> = 161)	(<i>n</i> = 143)
Absence	(reference)	(reference)
Presence	2.58 (0.85–7.81); 0.094	0.74 (0.32–1.69); 0.473
Scoliosis	(<i>n</i> = 158)	(<i>n</i> = 141)
Absence	(reference)	(reference)
Presence	1.16 (0.38–3.51); 0.793	0.50 (0.25–1.02); 0.058
Falls	(<i>n</i> = 158)	(<i>n</i> = 141)
Absence	(reference)	(reference)
Presence	0.27 (0.03–2.14); 0.214	0.86 (0.38–1.94); 0.711
Area	(<i>n</i> = 160)	(<i>n</i> = 141)
Urban	(reference)	(reference)
Rural	0.9 (0.29–2.79); 0.855	1.02 (0.49–2.16); 0.941
Mobility decline in the past year	(<i>n</i> = 158)	(<i>n</i> = 141)
Absence	(reference)	(reference)
Presence	2.97 (0.99–8.83); 0.050	0.48 (0.23–0.99); 0.048
Fatigue severity Scale	(<i>n</i> = 161)	(<i>n</i> = 143)
1–3	1.02 (0.99–1.05); 0.113	0.99 (0.98–1.02); 0.971
Surgery under 18	(<i>n</i> = 159)	(<i>n</i> = 142)
Absence	(reference)	(reference)
Presence	0.88 (0.28–2.77); 0.831	0.75 (0.37–1.50); 0.413
Surgery as an adult	(<i>n</i> = 161)	(<i>n</i> = 143)
Absence	(reference)	(reference)
Presence	1.67 (0.45–6.22); 0.444	0.61 (0.28–1.32); 0.206
GMFCS	(<i>n</i> = 132)	(<i>n</i> = 142)
I	(reference)	(reference)
II	0.37 (0.44–3.15); 0.364	0.61 (0.19–2.02); 0.421
III	0.88 (0.08–9.19); 0.916	0.44 (0.12–1.55); 0.203
IV	1	0.56 (0.15–2.04); 0.376
V	1 (0.06–17.62); 1.000	0.27 (0.05–1.42); 0.123

Bold text indicates $p < 0.10$.

is reduced after 18 years [16–18,22,23]. People with CP often have to find suitable physiotherapy services themselves, which is reported to be challenging [15,42]. A study that explored adherence to physiotherapy services using qualitative methods emphasised the importance of considering the personal preferences of adults by offering choice and being flexible to adults' needs [16]. Lack of choice and flexibility may partly explain why adults did not think physiotherapy met their needs. Qualitative studies described that adults with CP used physiotherapy to help with pain, stiffness and fatigue [16,17]. Our findings highlighted many other reasons for using physiotherapy. The most common were mobility decline (62%), stiffness (57%), and pain management (54%).

In the UK and Ireland, physiotherapy services can be accessed *via* public, private or charitable/voluntary service providers. In this sample, adults accessed physiotherapy mostly through public service providers (81%), followed by private practice (37%). One study from Australia reported that adults were concerned about the cost involved in accessing services [22]. However, there is a lack of studies that describe different types of service providers (i.e., public or private services) accessed by adults with CP, which is important for planning service development. Studies have shown that adults with CP often need ongoing specialist services to manage age-related changes [43,44], but face challenges in accessing specialised physiotherapy services [21]. In the current study, the majority of adults with CP visited non-specialist/general physiotherapy (40%), which may be due to the lack of physiotherapy services with specialist knowledge and experience in

supporting adults with CP. When adults with CP experience difficulties accessing specialist services or face a lack of clarity on service providers to reach out to, they typically seek support from their primary care providers [15,21]. This was consistent with our findings that adults were most commonly referred to physiotherapy services by their GP. In previous studies, adults with CP reported barriers to accessing physiotherapy included physical access barriers such as lack of transport, difficulty accessing car parking, and inadequate space or equipment in clinics [22,42]. Similarly in this sample, some adults (37%) reported being unable to access physiotherapy services because of inadequate transport or parking, which may have an impact on their satisfaction with services.

A recent review of services for adults with CP reported a lack of knowledge and expertise among health professionals about CP [15]. In this sample, 43% of adults reported their physiotherapists were not experienced in working with adults with CP. These findings were in line with a study from Sweden highlighting the lack of expertise in CP among physiotherapists working in adult services about CP [42]. A study in France reported that adults had lower satisfaction with motor rehabilitation compared to children with CP [25]. Our findings further highlight that the majority of adults with CP are not satisfied with the availability and quality of physiotherapy services. However, adults valued physiotherapy services when provided as they helped to manage symptoms related to CP [16]. Adults appreciated when physiotherapy services were flexible, personalized, with realistic targets and problem solved with adults, despite a lack of knowledge of CP [15,16].

There is also recent evidence to support interventions for adults with CP, which can help improve physiotherapy service delivery [45].

Our findings showed that in unadjusted analysis, people with mobility decline and pain were more likely to need physiotherapy. However, this was not observed in the adjusted analysis. In adjusted analyses, having scoliosis or experiencing a decline in mobility were negatively associated with receiving adequate physiotherapy. This may be because adults face challenges finding physiotherapy services that adequately address their mobility decline or scoliosis. A recent study from Ireland reported that 23% of adults with CP are not receiving the physiotherapy they needed to meet their needs [41]. Anecdotally, adults from both the UK and Ireland report receiving only a short course of physiotherapy from public service providers, for example, 6 weeks per year. This may be all that is available to adults with CP but may be insufficient for adequately managing scoliosis and decline in mobility.

Limitations

This study was limited to adults with CP who were able to complete an online survey with or without support, and therefore may not be representative of all adults with CP living in the UK and Ireland. It is acknowledged that the participants in this survey are under-representative of non-ambulatory adults in GMFCS levels IV and V, and those with cognitive impairment who were unable to complete the survey themselves or with support. People in GMFCS levels IV and V typically have profound cognitive impairments [46] and may have additional physical needs that are not adequately explored. A study from the Netherlands reported that ambulatory adults were more likely to use physiotherapy services compared to non-ambulatory adults [20] further highlighting the limited representation of adults with complex, non-ambulatory or severe CP. Participants were not asked to describe how they communicated in everyday life. The Communication Function Classification System [47] could have been included in the survey to classify communication at the activity/participation level and would have complemented the GMFCS data. The sample was also limited to adults who had accessed or tried to access physiotherapy as an adult. However, adults may also access treatment from therapists other than physiotherapists such as masseuses, chiropractors, and osteopaths to address CP complications. Further, the majority of data were gathered from participants in the UK, reducing the generalisability of the findings. There are differences in the health system between the UK and Ireland, including how people can access physiotherapy and the types of organisations that offer physiotherapy to adults with CP. However, there are also similarities between the two countries in terms of how services are provided to people with CP, such as the provision of coordinated multidisciplinary services to children with CP up to the age of 18 years, and the lack of adult rehabilitation consultants. Given the relatively small proportion of respondents from Ireland, there were insufficient data to present findings by country. Comparisons of need for physiotherapy, receipt of adequate physiotherapy, accessibility and satisfaction with physiotherapy between the UK and Ireland indicate that findings were similar. The use of a survey also limits the depth of data collected, and there is a need for further qualitative research examining the contextual factors that influence adults' experience of physiotherapy in the UK and Ireland.

Conclusion

Most adults with CP needed physiotherapy but many did not receive the physiotherapy they perceived they needed. Adults most commonly accessed physiotherapy for mobility decline but were not always satisfied with the physiotherapy they received. Adults also faced physical barriers to accessing physiotherapy services. The findings highlight a need to develop physiotherapy services in partnership with people with CP that meet their changing and ongoing needs across the lifespan.

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Ethical approval

The ethical approval was obtained from the Brunel University London's [Ref: 11389] and the Royal College of Surgeons in Ireland's [Ref: REC201910008] Research Ethics Committees.

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References

- [1] Colver A, Fairhurst C, Pharoah POD. Cerebral palsy. *Lancet*. 2014;383(9924):1240–1249.
- [2] Novak I, Morgan C, Adde L, et al. Early, accurate diagnosis and early intervention in cerebral palsy: advances in diagnosis and treatment. *JAMA Pediatr*. 2017;171(9):897–907.
- [3] Noten S, Troenosemito LAA, Limsakul C, et al. Development of an ICF core set for adults with cerebral

- palsy: capturing their perspective on functioning. *Dev Med Child Neurol.* 2021;63(7):846–852.
- [4] Nieuwenhuisen C, van der Slot WMA, Dallmeijer AJ, et al. Physical fitness, everyday physical activity, and fatigue in ambulatory adults with bilateral spastic cerebral palsy. *Scand J Med Sci Sports.* 2011;21(4):535–542.
- [5] Ryan JM, Peterson MD, Matthews A, et al. Noncommunicable disease among adults with cerebral palsy: a matched cohort study. *Neurology.* 2019;93(14):e1385–e1396.
- [6] Ryan JM, Allen E, Gormley J, et al. The risk, burden, and management of non-communicable diseases in cerebral palsy: a scoping review. *Dev Med Child Neurol.* 2018;60(8):753–764.
- [7] HAAK P, LENSKI M, HIDECKER MJC, et al. Cerebral palsy and aging. *Dev Med Child Neurol.* 2009;51:16–23.
- [8] Opheim A, Jahnsen R, Olsson E, et al. Walking function, pain, and fatigue in adults with cerebral palsy: a 7-year follow-up study. *Dev Med Child Neurol.* 2009;51(5):381–388.
- [9] van der Slot WMA, Nieuwenhuisen C, Van Den Berg-Emons RJG, et al. Chronic pain, fatigue, and depressive symptoms in adults with spastic bilateral cerebral palsy. *Dev Med Child Neurol.* 2012;54(9):836–842.
- [10] Bottos M, Feliciangeli A, Sciuto L, et al. Functional status of adults with cerebral palsy and implications for treatment of children. *Dev Med Child Neurol.* 2001;43(8):516–528.
- [11] Morgan P, McGinley J. Performance of adults with cerebral palsy related to falls, balance and function: a preliminary report. *Dev Neurorehabil.* 2013;16(2):113–120.
- [12] Ryan JM, Cameron MH, Liverani S, et al. Incidence of falls among adults with cerebral palsy: a cohort study using primary care data. *Dev Med Child Neurol.* 2020;62(4):477–482.
- [13] Thorpe D, Gannotti M, Peterson MD, et al. Musculoskeletal diagnoses, comorbidities, and physical and occupational therapy use among older adults with and without cerebral palsy. *Disabil Health J.* 2021;14(4):101109.
- [14] Parkes J, Donnelly M, Dolk H, et al. Use of physiotherapy and alternatives by children with cerebral palsy: a population study. *Child Care Health Dev.* 2002;28(6):469–477.
- [15] Manikandan M, Kerr C, Lavelle G, et al. Health service use among adults with cerebral palsy: a mixed-methods systematic review. *Dev Med Child Neurol.* 2022;64(4):429–446.
- [16] Redmond R, Parrish M. Variables influencing physiotherapy adherence among young adults with cerebral palsy. *Qual Health Res.* 2008;18(11):1501–1510.
- [17] Horsman M, Suto M, Dudgeon B, et al. Growing older with cerebral palsy: insiders' perspectives. *Pediatr Phys Ther.* 2010;22(3):296–303.
- [18] Jahnsen R, Villien L, Aamodt G, et al. Physiotherapy and physical activity – experiences of adults with cerebral palsy, with implications for children. *Adv Physiother.* 2003;5:21–32.
- [19] Park MW, Kim WS, Bang MS, et al. Needs for medical and rehabilitation services in adults with cerebral palsy in Korea. *Ann Rehabil Med.* 2018;42(3):465–472.
- [20] Nieuwenhuisen C, van der Laar Y, Donkervoort M, et al. Unmet needs and health care utilization in young adults with cerebral palsy. *Disabil Rehabil.* 2008;30(17):1254–1262.
- [21] Sandström K, Samuelsson K, Öberg B. Prerequisites for carrying out physiotherapy and physical activity – experiences from adults with cerebral palsy. *Disabil Rehabil.* 2009;31(3):161–169.
- [22] Morgan P, Pogrebnoy D, McDonald R. Health service experiences to address mobility decline in ambulant adults ageing with cerebral palsy. *J Intellect Dev Disabil.* 2014;39(3):282–289.
- [23] Moll LR, Cott CA. The paradox of normalization through rehabilitation: growing up and growing older with cerebral palsy. *Disabil Rehabil.* 2013;35(15):1276–1283.
- [24] Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol.* 2001;43(2):76–82.
- [25] Cornec G, Drownowski G, Desguerre I, et al. Determinants of satisfaction with motor rehabilitation in people with cerebral palsy: a national survey in France (ESPaCe). *Ann Phys Rehabil Med.* 2018;61:e58–9.
- [26] Barker K. Commission on the future of health and social care in England. London: The King's Fund; 2014. Available from: <https://www.kingsfund.org.uk/projects/commission-future-health-and-social-care-england>
- [27] Health Service Executive. Disability Services – Community and Social Care. Available from: <https://www.hse.ie/eng/services/list/4/disability/>
- [28] NICE. Cerebral Palsy in adults. National Institute for Health and Care Excellence (NICE); 2019 [cited 2020 Oct 7]. Available from: <https://www.nice.org.uk/guidance/ng119>
- [29] Department of Health. The national policy and strategy for the provision of neuro-rehabilitation services in Ireland 2011–2015; 2011 [cited 2020 Oct 6]. Available from: https://www.nai.ie/assets/58/0158D3D2-A34E-F708-15C6DBD7BA7D9126_document/NeuroRehab_Services1.pdf
- [30] Health Service Executive. National strategy & policy for the provision of neuro-rehabilitation services in Ireland. 2019 [cited 2020 Oct 6]. Available from: <https://www.hse.ie/eng/services/list/4/disability/neurorehabilitation/national-strategy-policy-for-the-provision-of-neuro-rehabilitation-services-in-ireland.pdf>
- [31] Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of internet E-Surveys (CHERRIES). *J Med Internet Res.* 2004;6(3):e34.
- [32] von Elm E, Altman DG, Egger M, et al. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *Ann Intern Med.* 2007;147(8):573–577.
- [33] Burns KEA, Kho ME. How to assess a survey report: a guide for readers and peer reviewers. *CMAJ.* 2015;187(6):E198–E205.
- [34] Beattie P, Dowda M, Turner C, et al. Longitudinal continuity of care is associated with high patient satisfaction with physical therapy. *Phys Ther.* 2005;85(10):1046–1052.
- [35] Fonteyn EMR, Keus SHJ, Verstappen CCP, et al. Physiotherapy in degenerative cerebellar ataxias: utilisation, patient satisfaction, and professional expertise. *Cerebellum.* 2013;12(6):841–847.
- [36] Hills R, Kitchen S. Satisfaction with outpatient physiotherapy: a survey comparing the views of patients with acute and chronic musculoskeletal conditions. *Physiother Theory Pract.* 2007;23(1):21–36.
- [37] Greig A, Bainbridge L, Bedard-Gutrais C, et al. An evaluation of patient-centred care elements that influence patient satisfaction in physiotherapy practice: a systematic review. *Physiotherapy.* 2015;101:e104.

- [38] Usuba K, Oddson B, Gauthier A, et al. Leisure-Time physical activity in adults with cerebral palsy. *Disabil Health J.* 2015; 8(4):611–618.
- [39] Jonsson U, Eek MN, Sunnerhagen KS, et al. Changes in walking ability, intellectual disability, and epilepsy in adults with cerebral palsy over 50 years: a population-based follow-up study. *Dev Med Child Neurol.* 2021;63(7):839–845.
- [40] Krupp LB, LaRocca NG, Muir-Nash J, et al. The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol.* 1989; 46(10):1121–1123.
- [41] Manikandan M, Casey C, Doyle A, et al. Use of health services and unmet needs among adults with cerebral palsy in Ireland. *Develop Med Child Neuro.* 2022. DOI:[10.1111/dmcn.15233](https://doi.org/10.1111/dmcn.15233)
- [42] Sandström K. The lived body – experiences from adults with cerebral palsy. *Clin Rehabil.* 2007;21(5):432–441.
- [43] Smith SE, Gannotti M, Hurvitz EA, et al. Adults with cerebral palsy require ongoing neurologic care: a systematic review. *Ann Neurol.* 2021;89(5):860–871.
- [44] Jahnsen R, Villien L, Aamodt G, et al. Musculoskeletal pain in adults with cerebral palsy compared with the general population. *J Rehabil Med.* 2004;36(2):78–84.
- [45] Gannotti M, Frumberg D, et al. Clinical therapy services for adults with cerebral palsy. In: Miller F, Bachrach S, Lennon N, editors. *Cerebral palsy.* Cham: Springer International Publishing; 2020. p. 1–24.
- [46] Reid SM, Meehan EM, Arnup SJ, et al. Intellectual disability in cerebral palsy: a population-based retrospective study. *Dev Med Child Neurol.* 2018;60(7):687–694.
- [47] Hidecker MJC, Paneth N, Rosenbaum PL, et al. Developing and validating the communication function classification system for individuals with cerebral palsy. *Dev Med Child Neurol.* 2011;53(8):704–710.